# NORMALIZATION FOR INDIVIDUALS WITH MENTAL RETARDATION

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## Background

Currently, service delivery for individuals with mental retardation is provided in accordance with the principle of normalization. Normalization means "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1976, 231). This principle implies that individuals with mental retardation have the same individual rights as any other citizen, and that there are services for them in the community. Given these implications in light of the long history of limited community based services to persons with mental retardation, one might expect parents to be particularly supportive of the normalization principle.

Yet, practice experience yields the observation that some parents are not supportive of the principle of normalization. One example of this lack of support is indicated by parental request for institutional placement for their son or daughter with mental retardation. Often the social worker, in complying with the principal of normalization and the policy of deinstitutionalization, will take on the role of advocate for the individual with mental retardation. Such a situation leads to discrepancies between the social worker and the family over the identification of needs and services for the individual with mental retardation. As a result, the social worker might be pitted against the parents in attempting to facilitate service delivery. Thus the question emerges as to what is the parental attitude about normalization. Furthermore, what factors influence parents' decision about residential placement for their son or daughter with mental retardation.

Because it offers an explanatory model for decision making, symbolic interaction theory is appropriate to use as a guide for focusing on the investigation of attitudes and decision making. This theory holds that experience coupled with knowledge from indirect experiences, combine to shape a person's perceptions. Perceptions in turn influence behavior (Blumer, 1969). Applying this theoretical premise to the situation of parental decision

making would result in the following argument. Parents' experience in caring for their son or daughter with mental retardation plus their understanding of the principle of normalization result in the parents' perception of the appropriateness of the normalization principle vis a vis their child's activities or living situation. This perception in turn influences parents' decision about residential care and thus their action to select a specific residential option.

## Related Literature

Previous literature regarding parental decision making about residential placement has focused on three areas. These areas include characteristics of the individual with mental retardation, family characteristics, and perception about residential service options.

Characteristics of the Individual with Mental Retardation

Although some socio-demographic variables (gender,age) have been found to be associated with parental decision about residential placement (Eyman et al., 1972; Farber et al., 1960), there has been no consistent trend documented. However, IQ and physical problems have been documented consistently in that individuals with lower IQ scores and individuals with physical disabilities are more likely to be institutionalized (Eyman et al., 1972; Justice et al., 1971; Skelton, 1972). Additionally, social behavior or difficulty in managing the individual with mental retardation has been associated with institutionalization (Eyman et al., 1972).

These findings related to characteristics of the individuals with mental retardation, suggest that parents' decision about out of home placement may be a function of the assessment of the extraordinary caregiving needs of their son or daughter in relation to their own ability (directly or by accessing support services) to meet those needs.

Family Characteristics

Several characteristics of the family system have been investigated in terms of their relationship to parents' decision about out-of-home placement. These characteristics include: parents' age, religion, health, educational level, income, marital integration, stress level, and the presence of siblings in the home.

Younger parents are more likely to request institutional placement (Wolf & Whitehead, 1965) due to overwhelming feelings of lifetime care needs of their son or daughter with mental retardation, recommendations of the physician, and the limited interaction with reference

groups that support the notion of family home care (Darling, 1979). Those parents who are affiliated with a religion, because they may receive both tangible and spiritual/emotional support that reinforces the idea that parents can provide the care in the home (Crnic et al., 1983; Darling, 1979) are less likely to request out-of-home placement. However, parents with poor health, especially the mother, may have a decreased ability to tend to the needs of the individual with mental retardation and thus a greater likelihood to request out-of-home placement in order to assure that those needs are met (Murphy, 1982). More highly educated parents are apt to request institutionalization presumably because their tolerance of deviance is limited (Holt, 1958). Likewise this rationale is used for parents in higher income levels who request institutionalization. Some literature suggests that request for institutionalization is a function of family income level or social class when parents attempt to assure that the needs of the individual with mental retardation are met and that the family's financial stability is maintained (Darling, 1979; Dunlap & Hollinsworth, 1977; Farber et al., 1960; Murphy, 1982). The presence of a handicapped individual has been shown to impact variously on marital integration (Berggreen, 1971; Dunlap & Hollinsworth, 1977; Fowle, 1968), stress and coping abilities of parents (Beckman, 1983; Birenbaum, 1971; Dunlap & Hollinsworth, 1977; Friedrich, 1979; Holroyd, 1979; Holroyd et al., 1975) and on behavior and roles of siblings (Berggreen, 1971; Dunlap & Hollinsworth, 1977; Farber et al., 1960).
Parents' assessment of the impact of the handicapped family member on the family system in turn influences parents' decision about out of home placement. Family characteristics, when viewed as contributors to the perception of caregiving capacity of parents, are explanatory factors in parental decision making about out-of-home placement.

Attitudes

Attitudes about mental retardation, residential service options, and normalization have been investigated in varying degrees, the findings of which generally support the institutional service model.

Darling (1979) found that families immersed in reference groups who defined their handicapped child positively also had positive attitudes about mental retardation whereas parents immersed in reference groups who defined their handicapped child negatively had negative attitudes. Thus, parents themselves possess a perception about the mental retardation and about the capabilities and rights of persons with mental retardation to be integrated into the community. It

seems logical to suppose that parents take in a myriad of factors when making a decision about residential placement for their son or daughter with mental retardation including their own perception of mental retardation and the community or the public response to mental retardation (Teeley, 1983; Woestendiek, 1983).

Additionally, parents' decision may be impacted by their perception of residential alternatives. Meyer (1980) found that parents chose institutions over other alternatives and their reasons included: the availability and quality of supervision, care and other resources. Payne (1976) found this same preference with the reasons being the concentration of professionals to provide services; the fact that the mentally retarded would be with persons like themselves; the protection from the stress of everyday life; and the permanence of the institution. These findings also concur with those of Woestendick (1983), Frohboese and Sales (1980), and Schodek et al. (1980) which indicate that the institution is viewed as one that is likely to persist because of the stable funding source. Further, parents report more continuity in programing in the institution because staff turnover is not particularly high as compared with group homes.

Ferrara (1979) specifically addressed parents' attitude about normalization. Parents displayed more positive attitudes about normalization when the referent was general and less postiive attitudes when the referent was their own son/daughter with mental retardation. Also, parents were in greater agreement with the values inherent in the normalization principle and in lesser agreement with the way the normalization principle was translated into community services. Ferrara concluded that parental attitudes need to be assessed so that areas of parental concern and conflict with professionals or public policy can be resolved.

Parents' decision about out-of-home placement is influenced by a wealth of information that arises from interaction with the individual with mental retardation as well as with others. Such information includes: parents' experiences related to caregiving; their beliefs about mental retardation and residential service options; their assessment of the family's goals and needs; and their understanding of the community's response to persons with mental retardation.

## Method

In an effort to understand parental perceptions about normalization and decision making related to residential

care, an exploratory study was conducted. This was a three (3) group correlational study using a survey research approach. The study was considered ex post facto in nature since parents' preference for residential placement had been documented prior to their participation in this study. Those parents who had requested institutional placement, those parents who had requested group home placement and those parents who had not requested out of home placement comprised the three groups.

The study subjects included parents of individuals with mental retardation who resided in the state of Maryland and whose names appeared on the waiting list for an institution (Great Oaks Center), for a group home (Baltimore Association for Retarded Citizens - BARC), and whose names appeared on an affiliation listing with BARC but who had not requested out-of-home placement.

A systematic stratified random sampling plan was employed to select subjects from the BARC waiting list and affiliation file. No sampling plan was used for the institutional waiting list since the N size of that group was so small. All persons on the institutional waiting list were invited to participate.

A total of 65 individuals responded to the mail questionnaire including 9 from the institutional waiting list, 28 from the group home waiting list, and 23 who were affilites of BARC (5 questionnaires were returned and completed with group affiliation unidentifiable. This total number constitutes a 35.7% response rate and takes into consideration those questionnaires that were returned undeliverable or unanswered. Such a response rate is not atypical for mail questionnaires (Babbie, 1973).

Instruments

The mail questionnaire contained three separate instruments, a demographic questionnaire and two test instruments. The demographic questionnaire consisted of items relating to characteristics of the parents, and characteristics of the individual with mental retardation including an estimate of the level of retardation and adaptive behavior. Test Instrument 1 was a 44 item revised version of Holroyd's Questionnaire on Resources and Stress (QRS). The QRS was used as a measure of parents' experience in caring for their son/daughter with mental retardation. The Second Test Instrument was a 20 item scale that measured attitude about normalization and which was developed by this writer based on the earlier work of Ferrara (1979), Gottlieb & Siperstein (1976), Gottlieb & Corman (1975), and Gottwald (1970). This scale attempted to document the degree to which the

respondent agreed with the philosophical aspects of normalization (rights) and to the actual operationalization of the normalization principle (ways of assuring those rights and integration in the community).

Both of the test instruments were reviewed by a panel for validity as well as clarity or readability and found to have face validity/content validity. A reliability assessment was conducted on the test instruments utilizing the study data. Item analysis using the Reliability program of the Statistical Package for the Social Sciences (SPSS)(Hull et al., 1975) provided an item total correlation and the Kuder-Richardson-20 (KR-20) reliability coefficient of .87 for the QRS which is the alpha for dichotomous variables (Friedrich et al., 1983) based on a total N size of 39 cases for which there was no missing data. The attitude about normalization scale also was exposed to a reliability test utilizing the alpha coefficient for continuous variables, as contained in the SPSS program. A Cronbach's Alpha of .76 was obtained on a total of 49 cases for which there was no missing data. Both reliability coefficients were considered within the acceptable range in order to proceed with data analysis.

Limitations

A number of methodological factors pose limitations to the results of this study. The data collection methodology being a mail questionnaire results in the respondents being a self-selected group and therefore not necessarily representative of the total population. Also, the N size of the sample was small thus further threatening the generalizability of the results. Although the three group design is theoretically sound, the groups may not be as distinct as had been hoped. A parent could have selected more than one kind of residential option and the decision about the residential option could have been influenced by a variety of other factors not accounted for in this study.

Despite these limitations however, the results do provide a beginning documentation of what this group of parents had experienced in caring for their son or daughter with mental retardation, and had thought about normalization. Indeed, if we are to provide a service delivery system that is efficacious, then we need to take into account parents' concerns and allow for these concerns to be included in the planning process.

## Findings

The Respondents

Table 1 displays the distribution of demographic

characteristics of the respondents according to their request for residential placement. Overall, the sample included parents who were older than those surveyed previously, those whose marriages mostly were intact, and those whose incomes were less than $20,001 per year. The majority of the respondents were Caucasian, had at least a high school education, were affiliated with some religious denomination and reported good or excellent health. Many respondents had another child living at home in addition to their son or daughter with mental retardation.

Table 1
DISTRIBUTION OF RESPONDENT CHARACTERISTICS ACCORDING TO DECISION ABOUT RESIDENTIAL PLACEMENT

| | NO PLACEMENT N=23 | GROUP HOME N=28 | INSTITUTION N=9 |
|---|---|---|---|
| Respondent | 69% mother | 71% mother | 55% mother |
| Average Age | 62 | 55 | 54 |
| Mar. Status | 56% married | 60% married | 77% married |
| Income | 73% <$20,001 | 73% <$20,001 | 28% <$20,001 |
| Occupation | 69& ret./hm | 44% ret./hm | 44% ret./hm |
| Education | 11 grades | 12 grades | 12 grades |
| Religion | 95% affil. | 100% affil. | 87% affil. |
| Race | 52% Cauc. | 75% Cauc. | 66% Cauc. |
| Health | 65% g/e | 64% g/e | 66% g/e |
| Oth. Sibs | 47% | 42% | 44% |
| Age-Sibs | 1-36 | 3-31 | 1-23 |

The Individuals with Mental Retardation

The characteristics of the individuals with mental retardation are presented in Table 2. In general, most of the individuals with mental retardation were over-age for special education services and were described as moderately mentally retarded. Most of these individual were considered to have adequate functional skills and to be fairly independent in self care skills but dependent in community living skills. Social behavior was reported as non-problematic.

Table 2
DISTRIBUTION OF CHARACTERISTICS OF THE INDIVIDUALS WITH MENTAL RETARDATION BY PLACEMENT DECISION

| | NO PLACEMENT N=23 | GROUP HOME N=28 | INSTITUTION N=9 |
|---|---|---|---|
| Average Age | 33 | 27 | 20 |
| Gender | 60% male | 53% male | 77% male |
| Degree MR | 82% mod. | 60% mod. | 55% mod. |
| Level Funct. | 48.2 | 49.8 | 40.3 |

Parental Experience in Caregiving

Test Instrument 1, the Questionnaire on Resources and Stress (QRS), consisted of eleven (11) subscales which measured the parents' report of stress. Subscales that clearly indicated stress for the majority of respondents were those of lifetime care and terminal illness. Subscales that reflected minimal stress included: family harmony, lack of personal reward, and physical limitations of the individual with mental retardation. Table 3 indicates that parents awaiting institutional placement reported the greatest amount of stress overall as well as for each subscale.

Table 3
AVERAGE SCORES OF THE QRS ACCORDING TO DECISION ABOUT RESIDENTIAL PLACEMENT

| | NO PLACEMENT | GROUP HOME | INSTITUTION |
|---|---|---|---|
| Dep./Man. | 1.1 | 1.7 | 2.1 |
| Cog. Imp. | 1.4 | 1.2 | 2.7 |
| Fam. Opp. | 1.4 | 1.7 | 2.5 |
| Life Care | 2.9 | 3.3 | 3.5 |
| Fam. Harm. | 0.3 | 0.7 | 1.0 |
| Lack Reward | 0.8 | 0.6 | 1.3 |
| Term. Ill. | 2.0 | 1.9 | 2.7 |
| Phy. Limits | 0.0 | 0.4 | 0.8 |
| Fin. Stab. | 1.6 | 1.5 | 2.5 |
| Inst.Pref. | 0.9 | 1.4 | 2.0 |
| Burd. Care | 1.9 | 2.3 | 2.3 |
| Total Score | 15.0 | 17.1 | 28.1 |

Attitude About Normalization

Respondents were asked to indicate on this 20 item scale, the degree to which they agreed with each statement that referred to the normalization philosophy. An average total score for each group was computed and found to be: 75.4 no placement; 77.5 group home; 70.4 institution. Testing for differences in the mean score for each of these three groups revealed no significant differences.

Because this result was not expected, the distribution of the responses for each item of the scale was re-examined. Those items for which a majority of the sample agreed included ones that addressed the philosophical or conceptual aspects of normalization (see Table 4).

Table 4
ATTITUDE ABOUT NORMALIZATION
ITEMS OF AGREEMENT

The individual with mental retardation:
- has the same basic needs as anyone else
- needs warmth and affection as anyone else
- has the same basic rights as anyone else
- should have an opportunity to pursue his/her desires
- has a right to a public education
- should dress like others his/her age
- should not be placed in an institution
- should expect to participate in community activities
- should have habilitation programs available to him/her

The majority of the sample also disagreed with those items that related to the manner in which the normalization principle is operationalized. Specifically, items addressing the integration of the individual with mental retardation into the community, the public school system, and the integration of "special services" with other community services were rated consistently as disagree or strongly disagree.

Hypotheses

A number of hypotheses were tested and the following results obtained.

H (1): The higher the QRS score the more likely the parent is to request out-of-home placement---supported.

H (2): The lower the attitude score, the more likely the parent is to request out-of-home placement---not supported.

H (3): The higher the QRS score and the lower the attitude score the more likely the parent is to request out-of-home placement---supported but probably due to the strength of the first hypothesis.

Other Analyses

A variety of other analyses were completed of which the following were found to be significant.

The higher the level of functioning of the individual

with mental retardation, the less stress reported by the respondent.
The younger parent is more apt to report higher stress.

The older the individual with mental retardation, the less likely the parent is to request out-of-home placement.

The higher the functional skills of the individual with mental retardation, the more positive the parents' attitude about normalization.

## Discussion

One of the initial questions that this study explored was what factors influence parents' decision about out-of-home placement.
Parents' decision about out-of-home placement for their son or daughter with mental retardation was found to be associated with the amount of stress that they experienced. The greater the amount of stress experienced, the more likely the parent was to request institutionalization. Parents indicated that in their experience of providing care for their sons or daughters with mental retardation, their greatest stress or concerns were the areas of lifetime care needs and terminal illness (ongoing health needs). Assurrance that the care and health needs of their children will be met may reduce the stress experienced by the parents. Such an assurrance can be given in the form of respite services being readily available and accessible to parents over the lifetime of the individual with mental retardation. Additionally, daily program services for adults could serve to decrease the stress. Early on, parents need to be advised of the range of services that are available. As time goes on, parents need this knowledge reinforced so that in fact they can take advantage of the available services. If the necessary services are not available or accessible, then efforts must be made to improve service delivery so that services can be utilized.

These concerns may also relate to the question of who will be responsible for the care of the individual with mental retardation when the parent is no longer able to provide the care. For some parents, the institution provides such an assurrance. Parents who did report the greatest amount of stress may have perceived some urgency in obtaining residential care for their son or daughter and therefore requested institutionalization in order to bypass the lengthy wait for community based residential services. Furthermore, parents may interpret the institution as being the most appropriate out-of-home

placement for those young (adolescent and younger) and significantly impaired individuals with mental retardation who present behavior management problems.

The other issue that this study investigated was that of parental attitude about normalization. Attitude was not found to be associated with decision about out-of-home placement, possibly because of the negatively skewed total scores on the attitude scale. However, the re-examination of the items on the attitude about normalization scale supported earlier work (Ferrara, 1979) in which parents agreed with the philosophical aspects of normalization but not with the way in which the principle is operationalized. It appears that parents prefer protection for their sons or daughters with mental retardation. Perhaps parents view integration of the individual with mental retardation into the community as too great a risk which may result in exploitation rather than growth toward independence.

The normalization principle assumes that that the community is accepting of individuals with mental retardation. Yet parents know through their own experience that the community is not as ready as the principle assumes (Woestendiek, 1983). Therefore, a review of the principle and its service options in light of parents' attitude and community readiness is critical if service delivery is to be efficacious.

Certainly, the attitude about normalization scale itself could be further developed so as to improve its reliabiltiy. Also, the inclusion of items that refer specifically to the adult population with mental retardation could result in a clearer understanding of parents' perceptions about the integration of their adult son or daughter into the community.

Because there is so little empirical information about parents' attitude about normalization, more widespread research to document that attitude is needed.

Given additional information on parents' attitudes about normalization, professionals, especially social workers, may be in a fine position to utilize this information to influence social policy. Involving the parents in the process of planning and designing of services that are consistent with normalization has the potential to result in services that will be utilized by the population for whom they were intended. Furthermore, another potential result might be a changed attitude about normalization by both the parents and the professionals involved.

The community too needs to be assessed for its readiness for the integration of individuals with mental

retardation. Efforts to enhance that readiness hould be made so that the physical integration also means social and psychological integration into the community (Frohboese & Sales, 1980).

Finally, professionals need to acknowledge the breakdown in the normalization syllogism ("normalization is best for the growth and development of individuals with mental retardation"; "parents want what is best for their children with mental retardation"; therefore parents want normalization") and to recognize the parents' perspective. Social workers in particular are trained to be good listeners. They need to listen to what parents are saying about their experiences and beliefs in caring for their sons or daughters with mental retardation. A partnership with parents needs to occur such that the "client" is redefined to include the parents as well as the individual with mental retardation. Thus, the social worker will not be pitted against the parent while attempting to provide services.

Parents' goals for their children are tempered by numerous factors including their experiences with their children, the service delivery system that is available, and the responses from the larger population. Perhaps by combining the pragmatism of the parents with the idealism of the professionals, effective advocacy can occur which will result in the physical, social, and psychological integration of individuals with mental retardation into the mainstream of society.

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